Living With Dementia: Care Partner Needs and Outcomes of a Dementia Support Program in Primary Care

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Abstract

To address the need for collaborative approaches to managing dementia in primary care, we implemented the Living with Dementia (LWD) program in a geriatric primary care clinic. This study evaluated the impact of short ($\leq$6 months) and longer-term (7+ months) participation in LWD on care partner outcomes (i.e., self-efficacy, depression, and burden) using *t*-tests and examined dementia support topics discussed with care partners through the intervention using deductive content analysis. Across 20 months analyzed, 57 dyads participated in the LWD program. Short and longer-term LWD participation indicated a significant increase in self-efficacy with small effect sizes; no changes were observed in depression or burden. Dementia support topics most frequently discussed with care partners focused on care partner well-being, behavior management, and offering referrals. This early evaluation suggests a collaborative care program integrated into primary care can address needs related to caring for persons with dementia and may improve care partner self-efficacy.

What This Paper Adds

- The Living With Dementia (LWD) program is a telephone-based care partner support program adapted from the Care Ecosystem model for a geriatric primary care setting.
- The role of the CTN enabled the LWD program to address several dementia care needs in the primary care setting including, care partner well-being, dissemination of information and disease education, and providing referrals as needed.
- Discussions between CTNs and care partners varied across stages of dementia, with dyads managing mild dementia more likely to discuss care partner well-being, specific referrals, and education; while care partners of PWD in moderate/severe stages more likely to discuss long-term services and supports.

Applications of Study Findings

- The LWD program offers insight on methods to support family care partners of PWD in the primary care setting.
- Collaborative care approaches employing CTNs may help provide effective dementia care in primary care by reducing the number of unmet needs experienced by dementia dyads.
- The LWD program may help to provide person-centered care due to the ability of CTNs to tailor information shared with care partners across the disease trajectory.

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Introduction

Alzheimer's Disease and Related Dementias are a prevalent and growing public health issue (Alzheimer's Association, 2022). Across communities, the burden of care coordination and disease management for persons with dementia (PWD) often falls on informal care partners (Olivari et al., 2020). Patients and their care partners, together referred to as a "dyad," often first speak with their primary care provider regarding cognitive impairment and memory related concerns (De Vreese et al., 2016). Due to long-standing patient-provider relationships, frequency of visits, and the ability to provide longitudinal care, primary care clinics are a vital setting for managing dementia and attending to care partner needs (Heintz et al., 2020; Mansfield et al., 2019). Yet primary care clinics often lack supportive services for managing dementia symptoms and resources for sharing disease related information and education with patients and their family care partners (Frost et al., 2021; Mansfield et al., 2019).

The Alzheimer's Association Dementia Care Practice Recommendations (Fazio et al., 2018) emphasize a need for collaborative approaches to managing dementia in primary care. Collaborative care models are characterized by multidisciplinary teams comprised to address the medical and psychosocial care needs of both PWD and care partners (Fazio et al., 2018; Larson & Stroud, 2021) . Collaborative care interventions in primary care show efficacy for reducing neuropsychiatric symptoms among PWD, in addition to caregiver burden among family care partners (Frost et al., 2020). The most common and effective collaborative care interventions in primary care clinics involve coordination with a trained dementia care manager (Frost et al., 2020; Heintz et al., 2020). Furthermore, collaborative care interventions in the primary care setting indicate feasibility and cost-effectiveness due to their ability to address a wide range of patient and care partner needs through consistent involvement from mild to later stages of dementia (Frost et al., 2021; Heintz et al., 2020).

Although there is a clear need for improved access to collaborative care interventions for managing dementia and supporting care partner needs in primary care (De Vreese et al., 2016; Larson & Stroud, 2021; Olivari et al., 2020), real-world implementation of such programs has been slow due to site and healthcare system barriers (e.g., stakeholder buy-in, training, and payment models) (Possin et al., 2019; Reuben et al., 2022). These barriers to care provision may lead to unmet needs for dyads as they navigate a challenging and complicated healthcare system (Mitchell et al., 2020). Further, unmet needs for information, education, and support may relate to reduced caregiver self-efficacy and greater emotional distress (Gallagher et al., 2011; Romero-Moreno et al., 2011), resulting in high health care costs and poorer quality of life for both patients and care partners (Alzheimer's Association, 2022; Mitchell et al., 2020; Olivari et al., 2020). To address the clinical need for access to collaborative care interventions for PWD and their care partners in primary care, we implemented the Living with Dementia (LWD) program. The program was adapted from the evidence-based Care Ecosystem dementia care model (Possin et al., 2017).

The Care Ecosystem Model

The Care Ecosystem model is a telephone-based intervention developed by Possin et al. (2017) which is designed to enhance dementia care management by providing care partner support and disease related information and education. The Care Ecosystem model uses a Care Team Navigator (CTN) to assess and tailor the intervention based on care partner needs throughout the various stages of illness (Bernstein et al., 2020; Possin et al., 2017). CTNs are an integral component of the Care Ecosystem model and are trained to provide dementia education, triage complex medical and social problems with appropriate referrals, screen for dementia related concerns, and provide care partner support through monthly telephone calls. CTNs serve as a primary contact for care partners and can refer to other disciplines within the health system or community-based organizations as needed. The Care Ecosystem model also includes a consultative, multidisciplinary team composed of a social worker, pharmacist, and a nurse who meet on a weekly basis with CTNs to offer additional insights and support. A randomized control trial ($N = 780$ dyads) utilizing this model found reductions in quality-of-life decline and hospital utilization for PWD, and a decrease in care partner depression and burden (Possin et al., 2019). The LWD program is a clinical demonstration project that adapted Care Ecosystem to integrate the program into everyday practice within an established geriatric primary care clinic whereby the CTN is a member of the primary care team.

Our objective is to describe the utilization of the LWD program and examine the potential clinical benefits for family care partners in terms of caregiver burden, depression, and self-efficacy in a real-world geriatric primary care setting. To illuminate the scope of the LWD program, we also aimed to explore the referral needs of dyads in the program by conducting a detailed evaluation of CTN documentation.

Methods

This study evaluated the LWD program from initial implementation in September 2018 through the end of the evaluation period in May 2021. The LWD protocol for this quality improving initiative was determined to be Not Human Subjects Research by the [Blinded for review] Multiple Institutional Review Board (#18-2163). The program is funded by [Blinded for review]

Setting and Participants

The LWD program was implemented in the [Blinded for review] which includes two academic geriatric primary care clinic sites located in [Blinded for review]. [Blinded for review] serves approximately 2800 patients with an average age of 84 years. The clinic sites include a multidisciplinary geriatric care team consisting of geriatricians, geriatric nurse practitioners and physician assistants, social workers, nurses, psychologists, medical assistants, and support staff.

[Blinded for review] primary care providers, social workers, and behavioral health providers referred PWD and their primary care partner for enrollment screening with the LWD program. Inclusion criteria included: (a) existing patient within the primary care clinic, (b) existing diagnosis of dementia, and (c) a care partner interested in participating. PWD who resided in long-term care facility (including assisted living residence or memory care) were excluded. Care partners were defined as the family member or friend most directly involved in the PWD's care. Enrollment in the program was voluntary.

Procedures

Upon enrollment, the CTN contacted the care partner for a comprehensive intake assessment and addressed any immediate needs, such as safety concerns or previously requested community referrals. Pre-COVID-19 pandemic the CTN also conducted an in-home visit to facilitate increased rapport, further assess dyad needs, and observe the home environment. However, this component of this program was terminated post-COVID-19. After completing the initial assessment, the CTN engaged with care partners via monthly phone calls. During calls, the CTN provided dementia information and education in response to relevant concerns voiced by care partners, offered strategies for navigating behavioral symptoms as needed, and provided resources based on the care partners' individualized needs or goals. The CTN also coordinated dyad needs with other members of the LWD program or primary care team. Community referrals were initiated by the CTN when necessary. New or challenging cases were discussed at weekly interdisciplinary meetings with LWD team members and other clinic providers including a social worker, pharmacist, and geriatrician. During these meetings, team members discussed potential non-pharmacologic approaches for dementia management, as well as clinic or community-based supports that might be relevant to the dyad. All CTN visits and phone calls were formally documented in the shared electronic medical record (EMR) by the CTN and routed to PWD's primary care provider for continuity of care.

Several adaptations to the Care Ecosystem model were implemented to facilitate application into the primary care setting. First, the CTN completed certification in the Resources for Enhancing Alzheimer's Caregiver Health in the community (REACH) program. All care partners received a REACH handbook. The REACH program and handbook has been shown to improve burden, and emotional and physical health of care partners (Elliott et al., 2010; Livingston et al., 2017). Second, home visits were a local adaptation to the Care Ecosystem model and were conducted until no longer safe in March 2020 due to the COVID-19 pandemic. After March 2020, the comprehensive intake assessment was telephone based only. Third, in addition to weekly interdisciplinary meetings with LWD team members and other clinic providers, the CTN supplemented Care Ecosystem resources with monthly meetings held with a gero-psychologist to enhance education for behavioral management shared with care partners. Fourth, instead of medication reconciliation by the CTN, calls directly from the clinic pharmacists to the care partner were integrated into the program workflow. Supplemental Figure 1 describes the overall workflow process for the LWD program.

Measures

PWD demographics were assessed from the EMR. The functional capacity of PWD was measured using the Functional Assessment Staging (FAST) upon program enrollment (Sclan & Reisberg, 1992). Care partners provided demographic characteristics at the time of enrollment. Care partner outcome measures were collected via phone or electronic survey at baseline and a follow-up time point (6 months, 12 months, or upon leaving the program due to transition to long-term care facility, dyad preference [termed "graduation"], or death of the PWD).

Zarit Burden Interview-12 (ZBI-12) was used to assess caregiver burden. The ZBI-12 includes 12 items on a 5-point scale, with higher scores representing higher feelings of burden. The ZBI-12 is a modified, shortened version of the original ZBI, a widely used instrument that addresses both personal and role strain and has been validated for use with informal care partners of community-dwelling PWD (Hébert et al., 2000). The ZBI-12 has demonstrated similar results to the original ZBI, has been validated for correlation of baseline and longitudinal follow-up (Bédard et al., 2001), and was selected for ease of telephone administration. The Patient Health Questionnaire-4 (PHQ4) was used for evaluating care partner depressive and anxiety symptoms. The PHQ4 is a 4-item survey, ideal for quick telephone assessment, has been validated in large population studies, and implemented in primary care (Kroenke et al., 2009; Löwe et al., 2010). The Care Ecosystem Caregiver Self-Efficacy Scale (Merrilees et al., 2020) was used for assessment of caregiver self-efficacy. This is a 5-item survey that asks participants to rate their self-efficacy on a 5-point scale from strongly disagree to strongly agree. Each question is scored 1 to 5 allowing
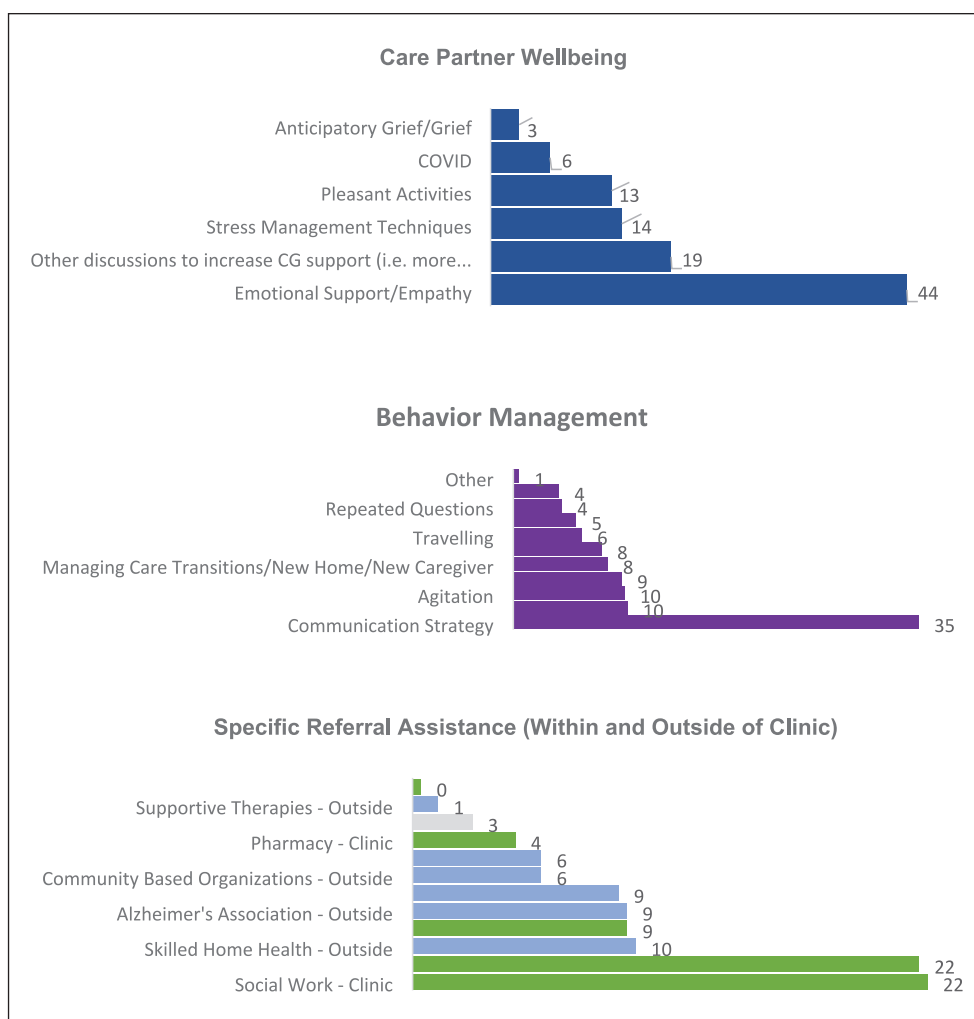
Figure 1. Frequency (%) of conversation subtopics occurring within the three most frequent conversation topics.
Note. PCP = primary care provider.

for a maximum score of 20 and higher scores representing greater feelings of self-efficacy. The scale was created for ease of administration over the telephone and compiled from other existing measures that have been correlated with care partner dementia symptom management, ability to access help, and care partner mental and physical health scores (Fortinsky et al., 2002; Jennings et al., 2015; Steffen et al., 2019). All data were stored in a REDCap database (Harris et al., 2009).

Analytic Strategy

Continuous and categorical variables were reported as means with standard deviation (SD) and percentages, respectively. To explore potential short and longer-term effects of LWD on care partner outcomes, care partners were grouped into clinically meaningful categories of short term and longer-term program participation. Short term use was defined as up to 6 months of LWD participation. Longer-term use was defined by follow up assessment occurring beyond 7 months. Care partner assessments at each time point were compared with Student's *t*-test and

effect size was determined using Cohen's *d* effect. Benchmarks for effect size were based on Cohen (1988): small = 0.2, medium = 0.5, large = 0.8. All tests for statistical significance were two-tailed, and a p-value of less than 0.05 was considered statistically significant. All analyses were conducted using SAS Version 9.4.

A qualitative deductive content analysis (McKibben et al., 2022) was completed with available CTN notes documented during monthly phone calls held with care partners. Content identified for the analysis included CTN documentation notes from September 2018 through April 2020 (20 months). A convenience sampling strategy was employed and included 15 CTN notes per dyad, allowing for analysis of approximately 1 year of program enrollment. Using a team-based, deductive coding approach (McKibben et al., 2022) two team members (HS, TJ) developed a coding scheme for dementia-related topics including dementia education, behavior management, long-term services and supports, ADL/IADL management, safety, care partner wellbeing, specific referral assistance, future planning, bereavement, and social determinants of health. The

Table 1. Patient and Care Partner Characteristics (*N* = 57).

Characteristic	Person with dementia (PWD), *N* (%)	Care partner, *N* (%)
Age, years (*SD*)	82.6 (6.5)	67.7 (13)
Disease duration, years (*SD*)	2.4 (2.4)	N/A
Female sex	35 (61)	44 (77)
Race		
American Indian/Alaska Native	0	1 (1.8)
Asian	3 (5.3)	3 (5.3)
White/Caucasian	44 (77)	43 (79)
Black/African American	6 (11)	6 (11)
Other	3 (5.3)	1 (1.8)
Hispanic	4 (7)	5 (9)
Education		
High school or less	17 (30)	4 (7)
Some college or Bachelor's degree	18 (32)	26 (46)
Post-graduate	22 (39)	27 (47)
Care partner type		
Spouse or partner	N/A	28 (49)
Child		26 (46)
Other family member		1 (1.8)
Friend		2 (3.5)
Care partner lives with PWD	N/A	44 (77)
Functional assessment staging test		
3 mild cognitive impairment	5 (8.9)	N/A
4 mild dementia	30 (54)	
5 moderate dementia	4 (7.1)	
6 moderately severe dementia	15 (27)	
7 severe dementia	2 (3.6)	
Caregiver burden (ZBI-12)		
No to mild burden (0–10)	N/A	12 (21)
Mild to moderate burden (10–20)		27 (47)
High burden (>20)		13 (22)
Missing		5 (8.8)
Care partner mood (PHQ-4)		
Normal (0–2)	N/A	24 (42)
Mild (3–5)		14 (25)
Moderate (6–8)		6 (11)
Severe (9–12)		2 (3.5)
Missing		11 (19)
		Mean (*SD*)
ZBI score, range 0–48 (*N* = 52)	N/A	16.0 (7.5)
PHQ-4 total score*, range 0–4 (*N* = 46)		2.84 (2.8)
Self-efficacy score, range 0–20 (*N* = 56)		9.95 (3.2)

Note. ZBI = Zarit burden interview 12; PHQ-4 = Patient Health Questionnaire; FAST = functional assessment staging tool; PWD = person with dementia; N/A = not applicable.
*PHQ-4 score is average rating of 4-items.

CTN notes were reviewed, topics were coded, and subtopics were identified. Definitions of topics and subtopics are listed in Supplemental Table 1. The coding scheme was established by double coding 57 notes of eight dyads and inter-rater reliability was established using Cohen's κ (Hallgren, 2012). The intercoder reliability of coding for the eight dyads was κ 0.79 (95% CI .73 to .85; $p < .001$), indicating substantial inter-rater agreement (Landis & Koch, 1977). Greater than 80% agreement was reported for 90% of codes. Conversation topics and subtopics were analyzed for frequency. The frequency of referral types, total number of referrals, referrals per dyad, and type of clinical care coordination within the primary care setting versus community referrals was calculated. Lastly, χ^2 analysis was completed to compare conversation topic frequency between PWD with mild FAST Stage versus PWD with moderate or severe FAST Stage.

Table 2. Care Partner Assessments Based on Length of Program Utilization.

Short-term participation (*N* = 25)

Assessment	Baseline	Up to 6 months	Effect size	
	Mean (*SD*)	Mean (*SD*)	(Cohen's *D*)	*p*-Value
ZBI total score	15.0 (6.3)	14.5 (7.9)	−0.038	.80
PHQ-4 total score	3.11 (3.2)	2.74 (2.6)	−0.065	.68
Self-efficacy total score	10.3 (3.1)	12.0 (2.5)	0.30	**.034**

Longer-term participation (*N* = 32)

Assessment	Baseline	12 months	Effect size	
	Mean (*SD*)	Mean (*SD*)	(Cohen's *D*)	*p*-Value
ZBI total score	16.2 (7.5)	15.3 (7.5)	−0.091	.48
PHQ-4 total score	2.88 (2.8)	3.14 (3.0)	0.083	.52
Self-efficacy total score	9.88 (3.2)	12.2 (2.6)	0.39	**.0018**

Note. ZBI = Zarit burden interview 12; PHQ-4 = Patient Health Questionnaire. *p*-value <0.05.

Results

Participant Characteristics

The characteristics of the 57 PWD and care partner dyads who participated in the LWD program during the evaluation period are shown in Table 1. The mean age of PWD was 82.6 years (*SD* = 6.5). Majority of PWD were female (61%), White (77%), with some college education or higher (71%). Dementia staging based on FAST varied from mild to severe, with mild dementia being most common (54%). Care partners had a mean age of 67.7 (*SD* = 13). Most care partners were spouse/partners (49%) or children (46%) with the majority living in the same household as the PWD (77%). Baseline assessment of care partner reported outcomes of burden, depressive symptoms, and self-efficacy are listed in Table 1. Most care partners scored in the mild-moderate level of burden range (47%). Twenty-five percent of care partners reported mild depressive symptoms; 11% reported moderate depressive symptoms.

Intervention Utilization

Of the 57 dyads, 32 utilized LWD services for at least 12 months while 25 dyads participated in LWD services for 6 months or less. Among dyads who utilized services longer, PWD were more likely to be in the mild stages of dementia (69% vs. 33%), whereas among dyads enrolled short-term, PWD were more likely to be in moderately severe stages (38% vs. 19%); these differences were statistically significant (*p* = .05) (Supplemental Table 2). There were no significant differences in care partner characteristics or baseline care partner assessments of burden, depressive symptoms, or self-efficacy between those who participated in the program up to 6 months versus 12 months (Supplemental Table 3).

Care Partner Assessments

Table 2 shows the change in care partner assessments from baseline to follow up assessment, by length of time in the LWD program. Caregiver burden did not change over time in either group. PHQ-4 scores also did not significantly change over time in either group. Caregiver self-efficacy scores significantly increased in both the short and longer-term groups, with small effect sizes (0.30 for short term, 0.38 for longer-term).

CTN Documentation Notes

A total of 491 CTN notes recorded in the EMR were included in the deductive coding analysis. Most notes had an average of 3 (*SD* = 0.6) conversation topics. The three most common conversation topics (Table 3) included care partner well-being (60%), behavior management (51%), and specific referral assistance (40%). The most common conversation sub-topics, (i.e., specific topics embedded within overarching categories), included care partner emotional support/empathy (44%) and strategies for communicating with a PWD (35%).

Figure 1 displays the sub-topic conversation frequencies for the three most common conversation topics. COVID-19 conversations represented only 6.4% of notes but when excluding the months prior to the pandemic, COVID-19 conversations were present in 40% of notes between February 2020 and the end of the qualitative study period in April 2020. When comparing conversation topics between dyads with mild dementia to dyads with moderate to severe dementia based on FAST Stage (Table 3), we found CTN interactions with the mild dementia group were more likely to focus on care partner well-being (*p* < .01), specific referral assistance (*p* < .05), and dementia education (*p* < .05). Among the moderate/

Table 3. Conversation Topic Frequency by Dementia Stage.

Conversation topic	All CTN notes (%)	CTN notes for PWD with mild FAST stage	CTN notes for PWD with moderate/severe FAST	
		N (%)	N (%)	p-Value*
Care partner well-being	293 (60)	234 (22)	59 (20)	**.0015**
Behavior management	247 (51)	187 (18)	60 (20)	.62
Specific referral assistance	197 (40)	159 (15)	38 (13)	**.013**
Dementia education	162 (33)	132 (13)	30 (10)	**.016**
Long-term services and supports	156 (32)	106 (10)	50 (17)	**.018**
ADLs/IADLs management	148 (30)	114 (11)	34 (11)	.44
Safety	91 (19)	75 (7)	16 (5)	.062
Future planning	41 (8)	32 (3)	9 (3)	.61
Bereavement	4 (1)	3 (0.5)	1 (0.5)	.99
Social determinants of health	4 (1)	3 (0.5)	1 (0.5)	.99

Note. N = 491 care team navigator notes. ADLs/IADLs = activities of daily living, instrumental activities of daily living; FAST = functional assessment staging tool.
*Comparing short-term and long-term participants. *p*-value <0.05.

severe dementia group, discussions more often centered around long-term services and support conversations ($p < .05$) compared to the mild dementia group.

The frequency of specific referral assistance ranged from one to eleven referrals, with 81% of dyads receiving assistance with at least one referral. Internal referrals to existing clinic resources were more common than external community service referrals (59% vs. 41%) with the highest prevalence being to social work (22%) and to PCP (22%). The most common referrals outside of the clinic were for skilled home health (10%) and the Alzheimer's Association (9%).

Discussion

This early evaluation of the LWD program demonstrated that the multidisciplinary collaborative program with a CTN integrated into geriatric primary care addressed a variety of needs among PWD and care partner dyads. As evidence of potential clinical benefit, early results showed a small improvement in caregiver self-efficacy. Although no statistically significant improvement in burden or depression was observed, it should be noted burden and depression did not worsen. It should be noted that baseline depression scores were low among care partners, which may restrict the potential range for detecting intervention effects. Together, the LWD program may be useful to provide care partners with appropriate education across the illness spectrum and to lend further support for emotional distress.

Our analysis found a small effect in caregiver self-efficacy among participants in LWD which may reflect the benefit of CTNs providing care partners disease information and education, including behavioral management strategies. These findings are consistent with other interventions targeting care partners of PWD, which found information and education, may enhance caregiver self-efficacy (Piersol et al., 2017). Although

intuitive, these findings hold significance within the broader clinical picture for improving self-efficacy as there may be secondary gains related to reducing care partner emotional distress and improving quality of care for PWD (Tang et al., 2016). As noted, these findings can be interpreted as providing demonstration evidence on the merit of additional testing, rather than evaluation of the efficacy of the LWD program.

LWD exemplifies several recommendations put forth across the literature regarding dementia care management for the primary care setting by providing a multidisciplinary collaborative program focused on care partner information, education, and support (Fazio et al., 2018; Larson & Stroud, 2021; Livingston et al., 2017). For example, analysis of CTN documentation notes revealed conversation topics varied across stages of dementia, with dyads managing mild dementia more likely to discuss care partner well-being, specific referrals, and education; while care partners of PWD with moderate/severe stages were more likely to discuss long-term services and supports. This finding highlights the multidimensional role of the CTN and moreover, the ability of the LWD program to provide tailored and specific information, education, and support to meet the broad and evolving needs of dyads across the illness continuum (Frost et al., 2021; Heintz et al., 2020).

Care partner well-being was identified as the most common conversation topic (60%) in CTN documentation, indicating the LWD program seemingly addressed an otherwise unmet need to support dyadic and individual needs in primary care. Additionally, care partners directed conversations with CTNs toward gaining information and education on challenging aspects of dementia care, as evidenced by 51% of CTN conversations with care partners consisting of behavioral management strategies. Although speculative, there is possibility these conversations contributed to improvements in caregiver self-efficacy.

CTNs facilitated various referrals to both in-clinic providers and outside community resources. Specifically, CTNs provided internal clinic referrals across 59% of conversations analyzed and community referrals in 41% of conversations. The number of in-clinic referrals provided by CTNs demonstrates the ability of the LWD program to maximize the capacity of the patient (family)-centered medical home approach to provide effective dementia care (Olivari et al., 2020). Moreover, the flexibility of the CTNs role allows for appropriate referrals to community resources, as well as specialty referrals when needed. The role of CTNs in providing tailored resources to dyads is a key component of the Care Ecosystem model which has been associated with high levels of care partner satisfaction (Possin et al., 2017). Across primary care settings, care coordination, limited time with dyads during appointments, and a lack of knowledge of supportive resources are frequently cited barriers to dementia care (Mansfield et al., 2019). The LWD program helped alleviate these barriers to dementia care in the current primary care clinic setting by providing broad information, disease education, and care partner support, as well as facilitating referrals for higher level of care or specialty services, when needed.

Over the course of the LWD program, we observed the collaborative care approach involving CTNs interacting with a multi-disciplinary team in the primary care clinic was a key component of the program implementation. First, referrals from within the clinic helped with ease of enrollment for providers and dyads by alleviating some of the burden placed on care partners to interact with multiple clinics. Second, communication between the CTN and care team was beneficial for bidirectional flow of information to tailor and enhance care. Shared access to the EMR supported communication between the CTN and providers, allowing for greater coordination of care. Other important facilitators to implementation were the ability to deliver the intervention via telephone to minimize disruptions during the COVID-19 pandemic and ensure the intervention reached homebound dyads (Bernstein et al., 2020). Finally, CTNs are trained and supported to provide dementia support and education and do not require formal licensure which allowed for recruitment from a diverse applicant pool of potential CTNs. For these reasons, LWD appears to be feasible for the primary care setting, especially in the context of value-based payment programs or reimbursement for chronic care management (Reuben et al., 2022).

Limitations

This study has several limitations. Importantly, because this clinical demonstration project enrolled a small number of dyads and did not compare the program to a control group, further study is needed to determine the effectiveness of the LWD program implementation into primary care settings. Also, attrition due to death or relocation to long-term care may have biased the sample towards dyads affected by mild dementia severity. Further bias may have been introduced as only one CTN was employed by the program during the study period analyzed. Additionally, conversation notes documented in the EMR did not capture all CTN interventions. Lastly, the impact of COVID-19 cannot be ignored, and though more than half of the dyads joined the LWD program prior to March 2020, many completed follow-up assessments during the on-going public health emergency. This may have impacted care partner experience of burden, mental health issues and sense of self-efficacy (Aledeh & Adam, 2020; Borelli et al., 2021). Together, findings from the current study may be biased and primary care stakeholders should consider other collaborative care interventions for dementia care in primary care as well.

Conclusions

The LWD program, adapted from the Care Ecosystem model, utilized an integrated CTN as a member of a geriatric primary care team to provide dyads living with dementia with information, education, and support. The program was utilized by dyads across the illness spectrum, ranging from mild to severe dementia, to address unique dyad needs and facilitate referrals for additional services. Further, care partners in the LWD intervention reported increased caregiver self-efficacy. Although further examination is required, the LWD program indicates potential for enhancing dementia care in a primary care clinic and we advocate for future research to target this intervention approach.

IRB Protocol/Human Subject Research Disclosure

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Supplemental Material

Supplemental material for this article is available online.

References

Aledeh, M., & Adam, P. H. (2020). Caring for dementia caregivers in times of the COVID-19 crisis: A systematic review. *American Journal of Nursing Research*, *8*(5), 552–561. https://doi.org/10.12691/ajnr-8-5-8

Alzheimer's Association. (2022). *2022 Alzheimer's disease facts and figures*. Author. https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf

Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit burden interview: A new short version and screening version. *The Gerontologist*, *41*(5), 652–657. https://doi.org/10.1093/geront/41.5.652

Bernstein, A., Harrison, K. L., Dulaney, S., Merrilees, J., Bowhay, A., Heunis, J., Choi, J., Feuer, J. E., Clark, A. M., Chiong, W., Lee, K., Braley, T. L., Bonasera, S. J., Ritchie, C. S., Dohan, D., Miller, B. L., & Possin, K. L. (2020). The role of care navigators working with people with dementia and their care partners. *Journal of Alzheimer's Disease*, *71*(1), 45–55. https://doi.org/10.3233/jad-180957

Borelli, W. V., Augustin, M. C., De Oliveira, P. B. F., Reggiani, L. C., Bandeira-de-Mello, R. G., Schumacher-Schuh, A. F., Chaves, M. L. F., & Castilhos, R. M. (2021). Neuropsychiatric symptoms in patients with dementia associated with increased psychological distress in caregivers during the COVID-19 pandemic. *Journal of Alzheimer's Disease*, *80*(4), 1705–1712. https://doi.org/10.3233/JAD-201513

Cohen, J. (1988). *The effect size. Statistical power analysis for the behavioral sciences* (pp. 77–83). Lawrence Erlbaum Associates, Publishers.

De Vreese, L. P., De Salvatore, L., Rovesta, L., & Fabbo, A. (2016). The management of dementia in primary care. In O. Capelli (Ed.), *Primary care in practice: Integration is needed* (pp. 69–92). IntechOpen. https://doi.org/10.5772/62762

Elliott, A. F., Burgio, L. D., & Decoster, J. (2010). Enhancing caregiver health: Findings from the resources for enhancing Alzheimer's caregiver health II intervention. *Joural of American Geriatric Society*, *58*(1), 30–37. https://doi.org/10.1111/j.1532-5415.2009.02631.x

Fazio, S., Pace, D., Maslow, K., Zimmerman, S., & Kallmyer, B. (2018). Alzheimer's association dementia care practice recommendations. *The Gerontologist*, *58*(1), S1–S9. https://doi.org/10.1093/geront/gnx182

Fortinsky, R. H., Kercher, K., & Burant, C. J. (2002). Measurement and correlates of family care partner self-efficacy for managing dementia. *Aging & Mental Health*, *6*(2), 153–160. https://doi.org/10.1080/13607860220126763

Frost, R., Rait, G., Aw, S., Brunskill, G., Wilcock, J., Robinson, L., Knapp, M., Hogan, N., Dening, K.H., Allan, L., Manthorpe, J., & Walters, K., & on behalf of the PriDem team. (2021). Implementing post diagnostic dementia care in primary care: A mixed-methods systematic review. *Aging & Mental Health*, *25*(8), 1381–1394. https://doi.org/10.1080/13607863.2020.1818182

Frost, R., Walters, K., Aw, S., Brunskill, G., Wilcock, J., Robinson, L., Knapp, M., Dening, K.H., Allan, L., Manthorpe, J., & Rait, G. (2020). Effectiveness of different post-diagnostic dementia care models delivered by primary care: A systematic review. *British Journal of General Practice*, *70*(695), e434–e441. https://doi.org/10.3399/bjgp20X710165

Gallagher, D., Ni Mhaolain, A., Crosby, L., Ryan, D., Lacey, L., Coen, R. F., Walsh, C., Coakley, D., Walsh, J. B., Cunningham, C., & Lawlor, B. A. (2011). Self-efficacy for managing dementia may protect against burden and depression in Alzheimer's care partners. *Aging & Mental Health*, *15*(6), 663–670. https://doi.org/10.1080/13607863.2011.562179

Hallgren, K. A. (2012). Computing inter-rater reliability for observational data: An overview and tutorial. *The Quantitative Methods for Psychology*, *8*(1), 23–34. https://doi.org/10.20982/tqmp.08.1.p023

Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap): A metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics*, *42*(2), 377–381. https://doi.org/10.1016/j.jbi.2008.08.010

Hébert, R., Bravo, G., & Préville, M. (2000). Reliability, validity and reference values of the Zarit burden interview for assessing informal care partners of community-dwelling older persons with dementia. *Canadian Journal on Aging*, *19*(4), 494–507. https://doi.org/10.1017/S0714980800012484

Heintz, H., Monette, P., Epstein-Lubow, G., Smith, L., Rowlett, S., & Forester, B. P. (2020). Emerging collaborative care models for dementia care in the primary care setting: A narrative review. *The American Journal of Geriatric Psychiatry*, *28*(3), 320–330. https://doiorg/10.1016/j.jagp.2019.07.015

Jennings, L. A., Reuben, D. B., Evertson, L. C., Serrano, K. S., Ercoli, L., Grill, J., Chodosh, J., Tan, Z., & Wenger, N. S. (2015). Unmet needs of care partners of individuals referred to a dementia care program. *Journal of the American Geriatrics Society*, *63*(2), 282–289. https://doi.org/10.1111/jgs.13251

Kroenke, K., Spitzer, R. L., Williams, J. B., & Löwe, B. (2009). An ultra-brief screening scale for anxiety and depression: The PHQ-4. *Psychosomatics*, *50*(6), 613–621. https://doi.org/10.1176/appi.psy.50.6.613

Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics*, *33*(1), 159–174.

Larson, E. B., & Stroud, C. (Eds.) (2021). *National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Health Care Services; Board on Health Sciences Policy; Committee on Care Interventions for Individuals with Dementia and Their Caregivers. Meeting the Challenge of Caring for Persons Living with Dementia and Their Care Partners and Caregivers: A Way Forward*. Washington (DC): National Academies Press (US).

Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., Ballard, C., Banerjee, S., Burns, A., Cohen-Mansfield, J., Cooper, C., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Larson, E. B., Ritchie, K., Rockwood, K., Sampson, E. L., . . .Mukadam, N. (2017). Dementia prevention, intervention, and care. *The Lancet*, *390*(10113), 2673-2734. https://doi.org/10.1016/S0140-6736(17)31363-6

Löwe, B., Wahl, I., Rose, M., Spitzer, C., Glaesmer, H., Wingenfeld, K., Schneider, A., & Brähler, E. (2010). A 4-item measure of depression and anxiety: Validation and standardization of the Patient Health Questionnaire-4 (PHQ-4) in the general population. *Journal of Affective Disorders*, *122*(1–2), 86–95. https://doi.org/10.1016/j.jad.2009.06.019

Mansfield, E., Noble, N., Sanson-Fisher, R., Mazza, D., & Bryant, J. (2019). Primary care physicians' perceived barriers to optimal dementia care: A systematic review. *The Gerontologist*, *59*(6), e697–e708. https://doi.org/10.1093/geront/gny067

McKibben, W. B., Cade, R., Purgason, L. L., & Wahesh, E. (2022). How to conduct a deductive content analysis in counseling research. *Counseling Outcome Research and Evaluation*, *13*, 156–168. https://doi.org/10.1080/21501378.2020.1846992

Merrilees, J. J., Bernstein, A., Dulaney, S., Heunis, J., Walker, R., Rah, E., Choi, J., Gawlas, K., Carroll, S., Ong, P., Feuer, J., Braley, T., Clark, A. M., Lee, K., Chiong, W., Bonasera, S. J., Miller, B. L., & Possin, K. L. (2020). The care ecosystem: Promoting self-efficacy among dementia family care partners. *Dementia*, *19*(6), 1955–1973. https://doi.org/10.1177/1471301218814121

Mitchell, S. L., Mor, V., Harrison, J., & McCarthy, E. P. (2020). Embedded pragmatic trials in dementia care: Realizing the vision of the NIA IMPACT Collaboratory. *Journal of the American Geriatrics Society*, *68*, S1–S7. https://doi.org/10.1111/jgs.16621

Olivari, B. S., French, M. E., & McGuire, L. S. (2020). The public health road map to respond to the growing dementia crisis. *Innovation in Aging*, *4*(1), 1–11. https://doi.org/10.1093/geroni/igz043

Piersol, C. V., Canton, K., Connor, S. E., Giller, I., Lipman, S., & Sager, S. (2017). Effectiveness of interventions for care partners of people with Alzheimer's disease and related major neurocognitive disorders: A systematic review. *The American Journal of Occupational Therapy*, *71*(5), 7105180020p1–7105180020p10. https://doi.org/10.5014/ajot.2017.027581

Possin, K. L., Merrilees, J., Bonasera, S. J., Bernstein, A., Chiong, W., Lee, K., Wilson, L., Hooper, S. M., Dulaney, S., Braley, T., Laohavanich, S., Feuer, J. E., Clark, A. M., Schaffer, M. W., Schenk, A. K., Heunis, J., Ong, P., Cook, K. M., Bowhay, A. D., . . . Miller, B. L. (2017). Development of an adaptive, personalized, and scalable dementia care program: Early findings from the Care Ecosystem. *PLoS Medicine*, *14*(3), e1002260. https://doi.org/10.1371/journal.pmed.1002260

Possin, K. L., Merrilees, J. J., Dulaney, S., Bonasera, S. J., Chiong, W., Lee, K., Hooper, S. M., Allen, I. E., Braley, T., Bernstein, A., Rosa, T. D., Harrison, K., Begert-Hellings, H., Kornak, J., Kahn, J. G., Naasan, G., Lanata, S., Clark, A. M., Chodos, A., . . .Miller, B. L. (2019). Effect of collaborative dementia care via telephone and internet on quality of life, care partner well-being, and health care use: The care ecosystem randomized clinical trial. *JAMA Internal Medicine*, *179*(12), 1658–1667. https://doi.org/10.1001/jamainternmed.2019.4101

Reuben, D. B., Evertson, L. C., Jackson-Stoeckle, R., Epstein-Lubow, G., Spragens, L. H., Haggerty, K. L., Serrano, K. S., & Jennings, L. A. (2022). Dissemination of a successful dementia care program: Lessons to facilitate spread of innovations. *Journal of the American Geriatrics Society*, *70*, 2686–2694. https://doi.org/10.1111/jgs.17900.

Romero-Moreno, R., Losada, A., Mausbach, B. T., Márquez-González, M., Patterson, T. L., & López, J. (2011). Analysis of the moderating effect of self-efficacy domains in different points of the dementia caregiving process. *Aging & Mental Health*, *15*(2), 221–231. https://doi.org/10.1080/13607863.2010.505231

Sclan, S. G., & Reisberg, B. (1992). Functional assessment staging (FAST) in Alzheimer's disease: Reliability, validity, and ordinality. *International Psychogeriatrics*, *4* Suppl 1, 55–69. https://doi.org10.1017/s1041610292001157

Steffen, A. M., Gallagher-Thompson, D., Arenella, K. M., Au, A., Cheng, S. T., Crespo, M., Cristancho-Lacroix, V., López, J., Losada-Baltar, A., Márquez-González, M., Nogales-González, C., & Romero-Moreno, R. (2019). Validating the revised scale for caregiving self-efficacy: A cross-national review. *The Gerontologist*, *59*(4), e325–e342. https://doi.org/10.1093/geront/gny004

Tang, W. K., & Chan, C. Y. J. (2016). Effects of psychosocial interventions on self-efficacy of dementia caregivers: A literature review. *International Journal of Geriatric Psychiatry*, *31*(5), 475–493. https://doi.org/10.1002/gps.4352